track 3: organising Participatory innovation

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introduction

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ABSTRACT

We describe our experiences employing experience-based design (EBD) to improve an outpatients health service in the UK and discuss the impacts of incorporating the voices of those not directly using or working within the service. We suggest that such new perspectives, experiences and expertise may enable the development of service innovations outside patients’ and staffs’ conceptual space of problems/solutions, but can affect the ownership and agency within the change project. To conclude, we propose a balance between accomplishing change and creating the self-belief to achieve it.

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together to promote the patient's health. Building on this concept, Open Health (Design Council 2006) recognises that people are active participants in their own healthcare, drawing services and information from a variety of sources (family, government, third sector, private sector etc.), and are uniquely placed to consider how healthcare services fit into their own lives. In this model, knowledge and expertise are seen as distributed, rather than solely the preserve of the clinician. This perspective resonates with the principles of participatory design (PD), where stakeholders are involved in the design of a system (or service) because: firstly they have a democratic right to be included; and because this results in systems and services that better fit their practices and needs (Ehn 1993).

Our research programme is based on a belief that user-centred or human-centred design (Buchanan 2001, Krippendorff 2006) can guide a rethinking of healthcare services and systems towards more human-centred models of care. Participatory methodologies then provide a means to design services that embody these new models. Understanding the design of health services in this way maps out three goals for UCHD, upon which our (action) research focuses:

1. Designing to improve existing services;
2. Designing service innovations; and,
3. Designing for strategic change.

Experience-based design is a participatory approach focusing on service improvement and as such provided the framework for our first case study.

EXPERIENCE-BASED DESIGN

Experience-based design (Bate and Robert 2007, NHS Institute for Innovation and Improvement 2010) was developed and is employed within the UK's NHS and can be regarded as the 'state of the art' for participatory service improvement within the NHS. Rather than being a single prescriptive method, EBD provides a range of techniques and tools within a four-phase structure for patients, carers and healthcare staff to work together to: capture and then understand their lived experiences of healthcare; improve a service based on this understanding; and measure the effects of change.

In the capture phase, EBD collects participants' stories, in their own words, using (for example) one-to-one interviews or video diaries. Patients, carers and staff then analyse the stories using 'emotional maps' to identify where improvements are required.

In groups, participants then share their stories and identify 'touchpoints' (points of interaction with the service such as a letter, a phone call, or a physical interaction with a person) and their feelings associated with them. Participants plot these touchpoints and emotions on a chart with the various stages of a patient's journey (or staff's working day) placed along the top. Positive emotions are placed nearer the top and negative emotions nearer the bottom. Clusters of negative emotions around touchpoints on the map suggest areas for improvement.

EBD suggests facilitating 'co-design' teams of patients, carers and staff to explore and implement service improvements, based on the understanding developed in earlier phases. Finally, evaluation of service improvements is shared with participants.

As the topic of this paper is the challenge of participatory innovation, we will restrict our discussion to the capture, understand and improve phases.

THE CHALLENGE OF PARTICIPATORY INNOVATION

Reviewing EBD prior to its use in our outpatients project, we felt that it would provide a powerful way of surfacing patients' and staff's experiences, through stories, and using stories to direct the service improvement. However we had concerns about how it could translate insights from experience into innovative design proposals. The illustrative examples given tended to be where patients and staff identified simpler issues where it was possible for them to take direct action themselves. For example, re-arranging chairs in a waiting area to improve the experience of waiting and moving sets of scales to increase patient privacy when being weighed (Bate and Robert 2007). This is acceptable if the aim is service improvement via refinement of existing practices and artefacts. However, we felt that it might limit the development of innovative design solutions that challenge the existing mechanics of the service and propose radical new ones.

This typifies a challenge that goes beyond EBD to PD more generally: how to devise products, services or systems that are both novel (innovative) and relevant to their likely users' practices and needs (Mogensen 1991). In PD, stakeholders and professional designers come together to explore a space for framing problems and devising solutions from their own perspectives, experiences and expertise. It therefore may be difficult to develop solutions outside this space (Bowen 2009).

In health service design, one way of dealing with this challenge could be to bring in those with radically different perspectives to patients and staff. We could construe such participants as 'voices from outside' where 'inside' is defined by those already using or working within the service. However, outside/inside divisions might be drawn in a number of ways. For example, in our outpatients project 'inside' could be defined as those patients, staff and design researchers who worked together throughout the project. But this could suggest a coherent 'inside' group that the 'voices from outside' differ from. We prefer to consider the idea of 'new voices being incorporated into the ongoing dialogues between participants, and affecting the change project, and participants roles within it, as a result. As we shall discuss below, the outpatients project brought together a disparate group of individuals with a variety of perspectives, experiences and expertises. The PD exercises were then an attempt to bring these different elements together and focus them on potential improvements. EBD provided the means of doing this via story sharing and co-design but, as we discuss below, has limitations that we addressed by drawing new voices into the process. Our discussion is then how these new perspectives, experiences and expertises were incorporated, how they served to expand the design activity, and how this altered participants' roles in the change process.

CO-DESIGNING OUTPATIENT SERVICES

Sheffield Teaching Hospitals NHS Foundation Trust obtained funding for a one-year service improvement project entitled Better Outpatients Services for Older People (BOSOP), which also provided an opportunity for us to ex-

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explore the EBD approach.

Rather, individuals’ understanding of the project and their role as change agents within it evolved throughout. Alliances were developed between participants, and individuals’ commitment to the project waxed and waned.

EBD recommends sharing emotional maps to establish a shared understanding between patients, staff and external facilitators. When patients shared their emotional map, staff’s initial reactions were to defend their service. For example, an ambulance dispatcher described the complex logistics that contribute to the delays to hospital transport reported by patients. We defused this situation by restating the aim to understand how it feels to be a patient or member of staff and not to apportion blame. As participants shared stories and experiences, occasional moments of opening up helped to build trust and common ground between the patients and the staff. For example, in their separate experience event, staff had placed “the book of bullshit” as a touchpoint on their emotional map. This referred to the numerous half-truths that staff sometimes gave to patients frustrated from waiting (the idea being that patients would feel better with any explanation for a delay rather than having none at all). For the upcoming experience event to be shared with the patients, the staff had planned to present their emotional map with a less provocative Post-it note labelled “standard excuses” over the top of “the book of bullshit”. However during the presentation (health support worker) Tracey revealed the original Post-it note and admitted the way staff actually thought of the situation, which prompted laughter and a release of tension in the room.

UNDERSTANDING EXPERIENCES

Two half-day ‘experience events’ were held: one for patients and carers, and one for staff to share their stories and produce emotional maps. At a third event the groups shared their maps (and stories) with each other and used them to collectively agree which areas of the service needed improvement.

IMPROVING EXPERIENCES

Participants formed two ‘co-design’ teams who met regularly over two months to discuss their agreed areas and propose improvements. At the end of this period a plenary event was held to review and prioritise the proposed improvements and divide them into a series of implementation projects.

TEAM BUILDING

As noted above, the patients, carers and staff involved in BOSOP were not a constant, coherent group focussed on improving the outpatients service. Rather, individuals’ understanding of the project and their role as change agents within it evolved throughout. Alliances were developed between participants, and individuals’ commitment to the project waxed and waned.
ing by, they came and lifted me up. They were fantastic. It shook me up. [...] I grazed my elbow and I grazed my hip but I didn’t break anything and we got in there and saw the doctor and I was okay. [...] You see I’m frightened of being late.”

Ruth, Patient

These and similar stories give an impression of the emotional responses. Ruth was shaken by her fall but the situation was exacerbated by her fear of being late. Consequently, facilities for dropping off patients (and parking) were agreed as key areas for improvement.

A co-design team agreed to investigate how this situation could be improved and mainly focussed on the congested area outside the outpatient building (A Road - fig. 1). The team did some fact-finding (on parking policies and allowances for taxis and disabled visitors), organised a ‘mystery patient’ visit by two of the group (one of whom had not visited previously), and drew up some ideas for new layouts of A Road. Although the team gathered additional details about A road and the experience of using it, they felt that they needed specialist expertise to translate their ideas into practical proposals. During the early fact-finding the UCHD team met Kevin, a hospital estates manager responsible for the roadways and signage. He told us that he had commissioned a safety study from the City Council’s Transport and Highways division and Richard the engineer who wrote this report, agreed to contribute his expertise to the design activity.

The previous study contained detailed recommendations to improve the safety of A Road but, although comprehensive, was written from an engineer’s perspective and did not reflect the experience issues revealed by patients and staff. For example, the study noted impaired visibility for motorists at road junctions but did not recognise that the existing layout of the area made dropping off patients extremely difficult. The implementation project then became two parallel activities. Jack (a patient) and Anne (a nurse) worked with the researchers to review the safety study and write an appendix detailing patient and staff experiences. In a separate design session with Richard they developed a new road layout proposal, using large-scale maps, paper and drawing materials (fig. 2). Richard then refined the proposal into a detailed technical drawing, which he & one of the professional researchers then presented to Kevin in the hospital’s estates department.

Kevin was enthusiastic about the proposal as being “achievable”, tying in to previous proposals (by the hospital and the city council), and having the potential to improve the situation. However he was unable to progress the proposal directly and undertook to discuss it with the hospital’s estates director.

DESIGNING AND TESTING WAY FINDING MAPS

“The very fact of going to hospital for something reasonably straightforward [...] can be a worry. [...] If you have got to wait for an appointment, there is that amount of time, for you to build up an emotional concern about it. Getting there is also [a] building-up of emotional tension. And then when you get there; I’ve had an ECG before. Even so, you know it’s uncomfortable. It’s a disturbance. It’s an emotional [...] roller coaster.”

Jack, Patient

Patients reported that getting information and assistance to locate the right hospital department (and confirmation when they got there) could be difficult and contributed further to the anxieties described by Jack (above) and others. A story shared by SCCCC illustrates this:

“I met this guy who [...] was lost, he was by the Dental Hospital [...] he said ‘well I’ve been for an appointment [...] and I couldn’t find it’ [...] he’d had a phone call and [...] he’d gone down on the bus and gone round to the front to A road and gone in at that entrance and he couldn’t find anybody to ask how to get to dermatology so they said ‘you need to go the main reception’ and he’d gone over to the main reception and [...] he said ‘they didn’t know where dermatology was and they sent me [...] to go and talk to the porters’ [...] whoever had directed him hadn’t done a very good job [...] I think he’d hovered around B road and then he’d realised it was about an hour and a half since [...] he should have been at dermatology so he gave up.”

Isobel, SCCCC Advocate/Carer

Like many UK hospitals, the Royal Hallamshire is a disparate collection of buildings that have grown and changed to meet the changing needs of the city’s population. A typical outpatient appointment includes going to one or more other departments in the hospital (e.g. blood tests, x-ray, pharmacy), so way finding is a concern both in getting to and during an appointment. In the experience events, patients placed signage as a pervasive concern on their emotional map and discussed how this related to their anxiety associated with
the visit. Staff also described spending a lot of time giving directions to patients and visitors who were passing through their department. On their emotional map, staff placed signage and a need to 'explain the system' (of when and where to wait) as key concerns.

A large part of the discussions in the co-design team consisted of describing the issues in more detail. The 'mystery patient' visit (see above) provided additional insights. By the plenary event, the team had collected rich evidence to argue that improvements were needed, but few suggestions of concrete solutions. They felt that it was difficult for them to devise solutions because they did not have relevant expertise. Instead, the UCHD project team proposed recruiting help from two postgraduate graphic designers from Sheffield Hallam University to devise new way finding materials. In the following weeks, the designers worked with Nigel (a staff member), Ruth (patient) and Dorothy (SCCCC advocate/carer) to design and review new signage and maps. Kevin (the estates manager) was also able to provide information on NHS way finding standards and guidelines and ongoing signage projects in the hospital, which had to be considered.

One of the proposals was a map for staff to give to patients with instructions on how to get to the cardiology department for an electro-cardiogram (ECG) (fig. 3). Although Nigel, Ruth and Dorothy had their experiences and comments considered in the design, other staff were highly critical when it was presented. At the end of the project, another version of the map was produced and left with outpatients' staff to evaluate. At the end of BOSOP, outpatients' staff still resisted handing out the map, although reception staff in the inpatient hospital building were keen to adopt it to and the approach for working with their patients.

**IMPROVING CUSTOMER CARE**

Throughout the story sharing, the regular social interactions between patients, carers and staff were identified as a critical aspect of patients' experiences. Rather than being associated with a specific touchpoint, this was a common theme and so no co-design team was tasked with addressing it. Instead, the UCHD project team, in consultation with managers at the hospital, responded to the issue by commissioning a local theatre group (Dead Earnest) to create an interactive learning event using applied theatre. The hospital provides 'customer care' training via an e-learning package, but it was evident that this approach was limited in addressing the negative experiences of participants and promoting positive behaviours. Brendan (Dead Earnest's artistic director) reviewed the stories and emotional maps, spent time observing the department, and spoke to (nurse) Anne and the project team about typical working days in outpatients. In response he devised a piece of drama titled ‘Don’t Lose Your Patients’, which followed a 'day-in-the-life' of an older patient and a member of staff in outpatients. The production paid particular attention to the back stories of ‘Eric’ (the patient) and the nurse whom he would meet later in the day as a device to bring out the complexity buried within the familiar and everyday. The event began with a play (scenes from outpatients) for an audience of staff and patients. Scenes were then replayed, and Brendan encouraged the audience to stop the action, challenge or comment on scenes and suggest changes in behaviour. Characters could be questioned to explore motivation and expectations, and a facilitated discussion followed each scene. Finally, the audience were asked to commit to making changes to their practice that were noted on postcards and returned to audience members as reminders. Feedback was very positive (“totally different way of training that works well”, “very good entertaining and enlightening”).

**DISCUSSION**

**IDEATION IN EBD**

Although EBD provided techniques that enabled participants to share perspectives and experiences and consequently identify areas for service improvement, it provided less guidance on how to design those improvements, in particular the process of 'ideation'. In the supporting Guide and Tools booklet for EBD (NHS Institute for Innovation and Improvement, 2010) there are 24 pages on capturing experiences, 22 pages on the understand phase, but just 12 pages on how to improve services and 8 on the measure phase. This deficit is something the developers of EBD themselves recognise (personal conversations with Helen Baxter, NHS Institute of Innovation and Improvement).

In their longer explication of EBD, Bate and Robert (2007) suggest an ideation method based on critiquing the design patterns or design rules inherent within a service. Based the ideas of Alexander (1977, 1979) and others, they conceptualise such patterns as the 'rules of thumb' or underlying principles of how a service works – the assumed 'whys' of the practices and processes within it. So:

“The broad task of EBD in this regard is to surface and examine the design rules in the light of the patient experience and consider which of them may need to be changed or added.” (ibid. p71)

Bate and Robert suggest that patients and staff can extract design patterns (and anti-patterns, that is misplaced or mistaken rules) from focused discussion around agreed touchpoints. To this end, EBD offers worksheets for participants to record identified design patterns and translate them into actions applying them to improve the service:

“If you want to achieve Y in situation S, something like X might help”

(Bate and Robert 2007, p152)

However, there are three limitations with using this approach.

Firstly it relies on surfacing patterns recognisable to participants from their experiences. These patterns may not
adequately account for the service issues they have identified and consequently may suggest solutions that fail to tackle more fundamental problems. I.e. problems and solutions are constrained within patients and staff’s existing ways of doing things.

Secondly, the design patterns approach is usually supported by the availability of an existing ‘pattern language’ (Dearden & Finlay, 2006), but the EBD materials do not provide any such starting point.

Thirdly, any actions that patients and staff propose might be limited to those achievable with their expertises – i.e. things that they perceive as actionable by themselves. This limitation is apparent whether the actions derive from design patterns or another strategy.

DIFFERENT VIEWS

In some parts of our outpatients project, patients’ and staffs’ perspectives, experiences and expertise were sufficient to identify where and how the service could be improved (such as re-writing the standard patient appointment letters to include useful and relevant information in a clear and accessible manner). However in each of the three cases above, we perceived that the efforts to address each problem had become stalled, with discussions in co-design meetings constantly returning to unravel and re-state problems (as the participants understood them) rather than towards discovering solutions.

Our hypothetical explanation for this was that patients’ and staffs’ conceptualisations of problems and solutions (as a design patterns approach could produce) were restricted by their experiences and therefore were not leading them to ideas for innovation. We recognised that participants might lack the technical skills to develop certain service improvements, and therefore we chose to involve new participants to bring new perspectives and experiences.

In both the road layout and way finding examples, participants agreed that they needed additional expertise to develop solutions. We consequently engaged the traffic management engineer and the two graphic designers. In becoming participants in the outpatients project, the engineer and graphic designers also brought their own perspectives on the work, which influenced the form and content of the proposals. For example, the proposal developed for a road included the radical step of reversing the (one-way) flow of traffic. The proposals also re-presented patients’ experiences in a format that was sympathetic to existing working interactions between the engineer and estates department, i.e. in the form of a traditional report and plans. The proposal also attended to the engineer’s knowledge of the legal framework of safety regulations.

But these new participants did more than provide skills to create these artefacts from patients’ and staffs’ ideas. They could also draw on different experiences and introduced new representative artefacts to support the discussion, such as the formal technical reports, traffic flow maps, block graphics etc. The added expertise can also suggest alternative strategies for tackling the identified issues (such as using hand-out maps in addition to signage), and to raise new aspects of the problems for resolution (such as managing any impacts on traffic flow outside the hospital grounds).

As we have argued elsewhere, design can be understood as a dialogical process composed through ‘material utterances’ (Dearden, 2006). The utterances introduced in each case, extend the dialogical encounter of the participants, and so open up the awareness of all the dialogue participants to other possibilities for solutions.

Thus these different views provide new framings of both problems and solutions.

BROADENING THE PROBLEM/SOLUTION SPACE

The perspectives, experiences and expertise of each participant (ourselves included) map out a dynamic space in which problems can be framed and solutions devised – what constitutes a problem, what solutions strategies can be adopted, the criteria for success, and (overarching all) the aim of the project itself. The story-sharing, emotional mapping and co-design activities in EBD are then a dialogical process where participants come to an understanding of each other’s perspectives, experiences and expertises and, in doing so, map out a broader (and different) problem and solution space. As the team forms, the range of ideas that are open for consideration is extended.

However the collective perspectives, experiences and expertises of the participants implicitly bound this space. It is difficult to devise solutions (and problem framings) that are not recognisable or familiar to at least one of the participants. Moving from service improvement to service innovation often requires consideration of radical possibilities that are outside of what is initially perceived as the solution space. Bringing in participants with different perspectives, experiences and expertise, and using new representational artefacts, reframes the space of the dialogue to broaden the space under consideration.

In the customer care example, the applied theatre group Dead Earnest saw their role as to re-present patients and staff’s experiences rather than put forward their own. Rather than technical skills for executing and developing participants’ design proposals, the expertise they brought was concerned with how human reflective communication can prompt reflection and revision of people’s behaviour. Within this, Dead Earnest used comedy and drama to provoke debate amongst the staff audience. They aimed to be faithful to the stories they heard from patients and staff whilst presenting caricatures of familiar scenarios.

Again, there is a dialogical process taking place. But in this case the dialogue was between the staff on the taken-for-granted aspects of their practices, as facilitated by the theatre performance. Dead Earnest de-familiarized these practices and made them accessible as a subject for discussion.

OWNERSHIP AND AGENCY

We brought new voices into BOSOP in order to move forward on improving the outpatients service. However, these new participants also shifted the ownership and agency of the change process.

In the way finding example, the graphic designers created the new signage and maps in consultation with the patient and staff representatives. This shifted the existing participants’ involvement from co-creation towards a less ‘hands-on’ role – briefing the designers and feeding back on their proposed designs. On one level, this might be regarded as reducing the agency of the patients and staff because they were less directly in-
volved in the design activity. However, an alternative view is that their agency was increased by the recognition that they could work together with talented and skilled people to promote larger changes.

The proposal for a new road layout was a more collaborative effort between the patient and staff representatives, the traffic management engineer and the project team's designers. Here, existing participants remained fundamentally involved in co-creation but were able to draw on the expertise of the engineer and so extend their capabilities.

In the final case of the applied theatre work, the patients and staff had only a minor role as information providers in an initiative. The applied theatre company's aim was for staff to take ownership of improving customer care by committing to change their practices. Following the event, the only formal actions were those staff recorded on postcards for their later reference.

These three examples illustrate different levels of agency in the change process. If the sole aim of our outpatients project was to improve the service (Ehn's technical feature of PD), patients and staff's sense of agency might not be as significant as ensuring the project had the relevant skills to accomplish change. However, the outpatients project was also about creating a political force for change within the hospital, as exemplified by the applied theatre work. In this respect, patients' and staffs' reduced agency could undermine their self-belief in enacting change.

In participatory health service improvement projects such as ours, there could then be a tension between service innovation and building a political force for organisational and cultural change. Including new voices in the project impacted on existing participants' agency but it did have advantages. Our interactions with (hospital estates manager) Kevin not only brought in technical expertise to the way finding and work, it also involved a key stakeholder who would be directly involved in implementing any proposed changes. This was likewise the case with (traffic management engineer) Richard. In participating, Kevin and Richard increased the likelihood of change but also became part of a political force for change within the hospital and Sheffield City Council. Their involvement also legitimised the experiences and ideas of patients and staff, whilst the reports of patient and staff experience will in future serve to legitimise arguments for future redesign of traffic flow.

Perhaps there is then a balance to be struck between the change agency of those directly impacted by a health service, and the potential to enact such change. Within this, a way of encouraging patients and staff to become a political force for change is to ensure that they retain ownership of the change process, but also to recruit a wider coalition for change. In our outpatients project, we attempted to do this via ongoing dialogue with participants in events, newsletters and other communication materials (with, as described, mixed success).

CONCLUSIONS

Returning to the goals of user-centred healthcare design outlined in our introduction, BOSOP demonstrated that experience-based design has value as an approach for designing service improvements (the first goal) but has limitations, in its current form, for service innovation.

Methodologies that use stakeholder participation, such as EBD, map out a space for framing problems and devising solutions through dialogues between participants as differently-placed experts. The collective perspectives, experiences and expertises of stakeholders bound this space and could limit the development of novel services outside of it. Those who can offer radically different perspectives (and bring new experiences and expertise) can broaden this problem/solution space and open the way to service innovation. However, as we found in our outpatients project, bringing new voices into an ongoing participatory service design project impacts existing participants' ownership of and agency within the change process, particularly if these new participants are not directly using or working within the service.

As those engaged in the participatory design of healthcare services, we need to balance the aims of our work between achieving radical change in specific services and fostering a political force within healthcare institutions with the self-belief to transform practice. It may be that only through a combination of both these technical and political features that innovative health services based on new models of care can result.

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REFERENCES